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Missouri Planning Council

Current and Former Residents of Bellefontaine Habilitation Center:

A Survey of the Families and Guardians

***Brief Report Number 1
On the Well Being of People Affected by the Announced Closure of
Bellefontaine Habilitation Center:
Changes in Quality of Life
Among Those Who Moved and Those Who Stayed***

Submitted to:

Missouri Planning Council for Developmental Disabilities

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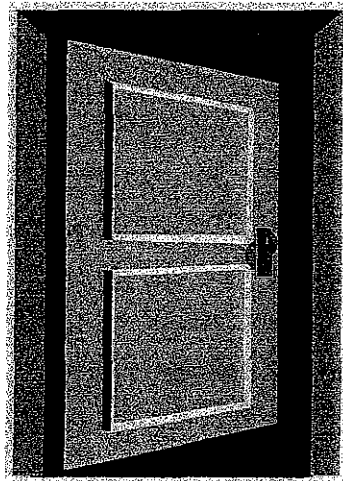
July, 2007

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Introduction and Summary

This report contains the results of a mailed survey of the families of the people who were living at Bellefontaine Habilitation Center in 2005. In this report, we focus on the general question “Are the people better off?” in the opinion of the families and guardians.

We did the survey, by mail, in 2007. We sent questionnaires to the closest relatives and guardians of the former and current residents of Bellefontaine. The survey was performed because Governor Blunt had announced the intention to close Bellefontaine in January 2005.

Under my budget, Missourians with developmental disabilities would enjoy a higher quality of life in a less restrictive environment, instead of in a state-operated institution. I support plans to expand private-sector community placements through closure of the state-operated Bellefontaine Habilitation Center. These actions will save the state \$13.8 million and benefit Missourians with developmental disabilities.

Excerpt from Governor Matt Blunt's State of the State Address, January 26, 2005

The people who lived at Bellefontaine Habilitation Center (BHC) all had significant intellectual disabilities¹, and most of them had additional disabilities – sensory, physical, and medical. People living in BHC and other public institutions, both in Missouri and throughout the United States, are among the most vulnerable of our citizens. Hence, changes in public policy require close scrutiny to ensure the well-being and proper support of these citizens. The survey reported here is one part of an effort to track changes in the lives of the people affected by the Governor's order.

This report contains the results of the survey, written in non-technical, user-friendly language. In general, the survey revealed that the families believe their relatives who lived at Bellefontaine are doing quite well – as well as before, and in many ways, slightly better than before – no matter whether they moved or not.

It appears that quality at BHC improved somewhat, probably because of the reduction of the number of people living there, and possibly other factors such as renovations and enhanced staff training.

¹ The newer term for “mental retardation,” illustrated by the change in the name of the President's Committee on Mental Retardation to the President's Committee on People with Intellectual Disabilities.

Many people left BHC, but rather than move to small community homes, they went to other large facilities. The families of these people generally think their relatives have experienced mixed results – some good, some not so good – with no overall improvement in quality. On the whole, they are no worse off than they were before, and families seem to be happy about that.

The families of the people who moved to small community homes in regular neighborhoods appear to see the biggest positive changes. They believe their relatives are much better off than they were at BHC, and are most impressed with increased happiness and freedom among their relatives.

These findings arise from very small numbers of families – and therefore every finding should be regarded as tentative. We cannot be certain that the few families and guardian from whom we obtained completed surveys are representative of all the families and guardians. However, the findings from this small survey are very similar to the findings of many larger studies in other states and other nations.²

At the end of this document, we have included two Appendices. The first is a copy of the survey form we sent to the families. The second is a scholarly review of past studies of this same issue – how families react to the idea, and the reality, of the movement of their relatives from one living situation to another – particularly about people moving from large state-operated institutional settings to small, privately run community based homes. These two Appendices are included for future reference, as Missouri will probably continue to explore alternatives to large segregated institutional models.

² See Appendix B for a review of research in this area.

Results of the Survey

The main goal of the survey was to gauge the opinions of all the families and guardians of the more than 200 people living at BHC. BHC set out requests for consent in late 2006. We obtained consent from 100 families and guardians. This was roughly half of the residents of BHC at the time.³

We sent out survey forms to all 100 consenting families in April 2007. Of the 100 families, 31 completed and returned the survey forms. The completed surveys broke down as follows:

Chart 1: Living Situations of the BHC People

Living Situation	Sent Out	Received Back
BHC	44	16
Other Institutional	15	9
Community	29	6
Unknown	12	0
Total	100	31

We received 31 completed surveys out of 100 sent; this is 31%, which is slightly lower than in other comparable surveys.⁴ It is important to note that these numbers are quite small. *The conclusions drawn from this survey will have to be viewed with great caution.* Although there is no better information available about the feelings of families, we must not assume that these few surveys are perfectly representative of all. In other words, we think this is probably the best information anyone has, but its limitations must be kept in mind.

³ Respect for confidentiality required that we not know about the families and guardians until they gave their consent. So we cannot calculate the exact percentage of families who did and did not give consent.

⁴ For example our 1998 survey of families in Oklahoma resulted in a 36% response to the first mailing.

About half the people who responded to the survey were mothers. Others who responded included guardians, fathers, siblings, and other relatives as described in Chart 2.

Chart 2: Relationships of Respondents to the Current and Former Bellefontaine Residents

Relationship	Number	Percent
Mother	15	48%
Unrelated Guardian	5	16%
Mother And Father	3	10%
Sister Or Brother	3	10%
Other Relative	3	10%
Father	2	6%
Total	31	100%

About a sixth of the respondents were guardians. This is not surprising, because many of the people who live in public institutions no longer have any living relatives who keep in contact.

The next chart shows the ages of the responding families and guardians.

Chart 3: Age Group of Families and Guardians Who Responded

Age Group	Number	Percent
Under 20	0	0%
20-29	0	0%
30-39	1	3%
40-49	2	7%
50-59	5	16%
60-69	11	35%
70-79	10	32%
80 or older	2	7%
Total	31	100%

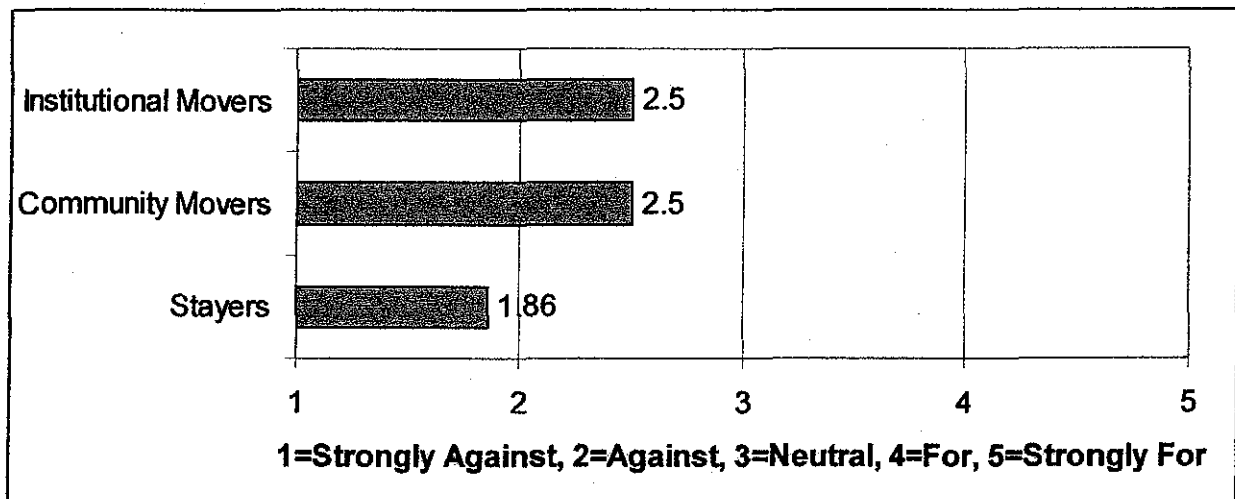
The respondents to our survey were in the upper age range, and their relatives had lived at BHC for a very long time. About three fourths of the family respondents were 60 or older. This is also shown by the next item in the survey, which asked how long the relatives had lived at BHC. The average was about 25 years. About a third had been there for more than 33 years. Only two people had been there for less than 10 years.

We asked families about their contact with their relatives over the past year. We asked about telephone, mail, visits to the person, outings with the person, attending program planning meetings, and giving consent for medical care. The small numbers in our survey permit a cautious finding: the families of people who moved to the community have had the most contact (about 30 events in the past year). Next were the families of the people who moved to other institutions at about 20 events, followed by the people who stayed at BHC at about 10.

This pattern makes sense; people who moved tended to have the most contact with family because they were in a period of transition and concern. And the people who moved to community homes had even more contact because their new homes were very different from the old institutional model. We suspect it was very important for the families to personally make sure that the new community homes were meeting their relatives' needs.

The next items on the survey asked about the families' feelings when they first heard that their relatives might have to move out of BHC.

Chart 4: Feelings When First Heard About Moving to a New Home



The above chart illustrates the resistance among relatives and guardians to the idea of movement. When informed that the people were all going to be uprooted after having been at BHC for so long they were understandably opposed. And, among the three groups, the most opposed were the families of those who actually remained at BHC.

The next chart shows the feelings that the families have toward their relative's current home.

Chart 5: How Do You Like Your Relative's Home Now?

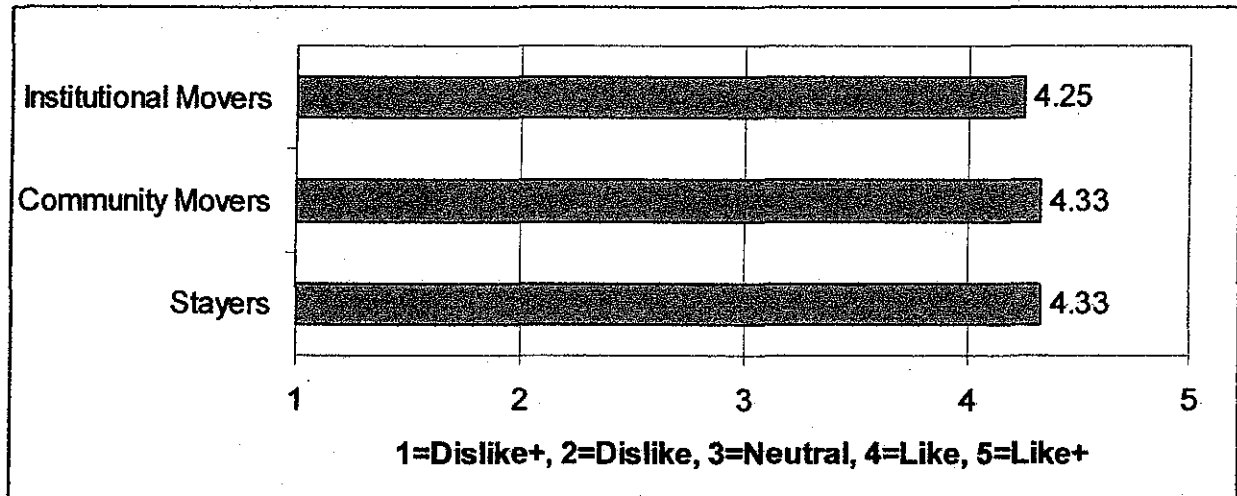
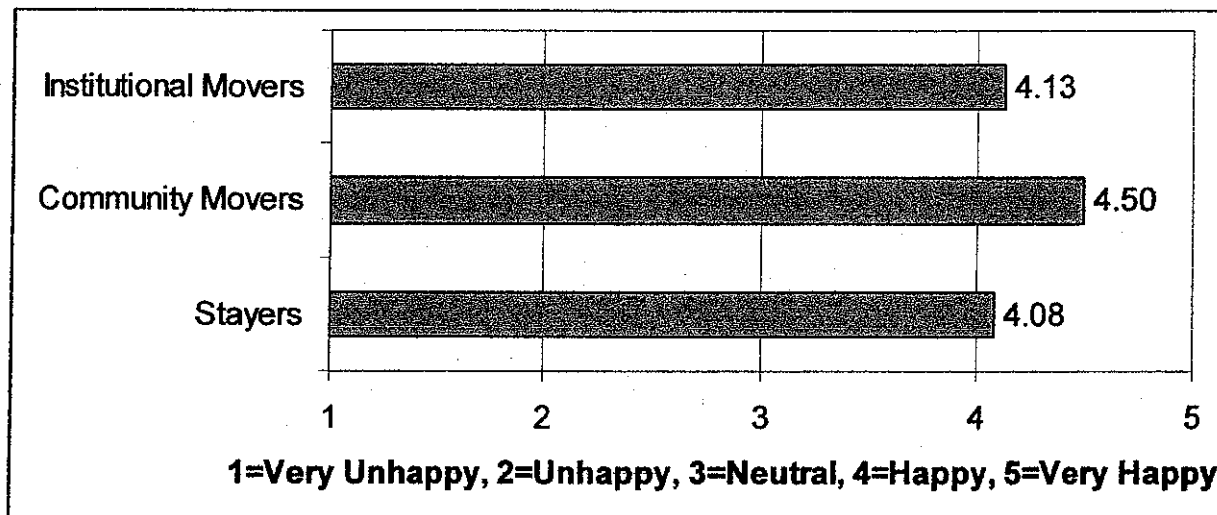


Chart 5 is a graphical representation of the average rating that relatives and guardians have towards the relative's new home. The families of all three groups seemed quite content with their relatives' homes, with the ratings falling between Like and Like A Lot.

The chart below shows the averages of the answers to the question "*How happy do you think your relative is with his/her current living situation?*" The answers were given from 1 to 5, with 1 meaning Very Unhappy, up to 5 meaning Very Happy.

Chart 6: How Happy Do You Think Your Relative Is With His/Her Home?

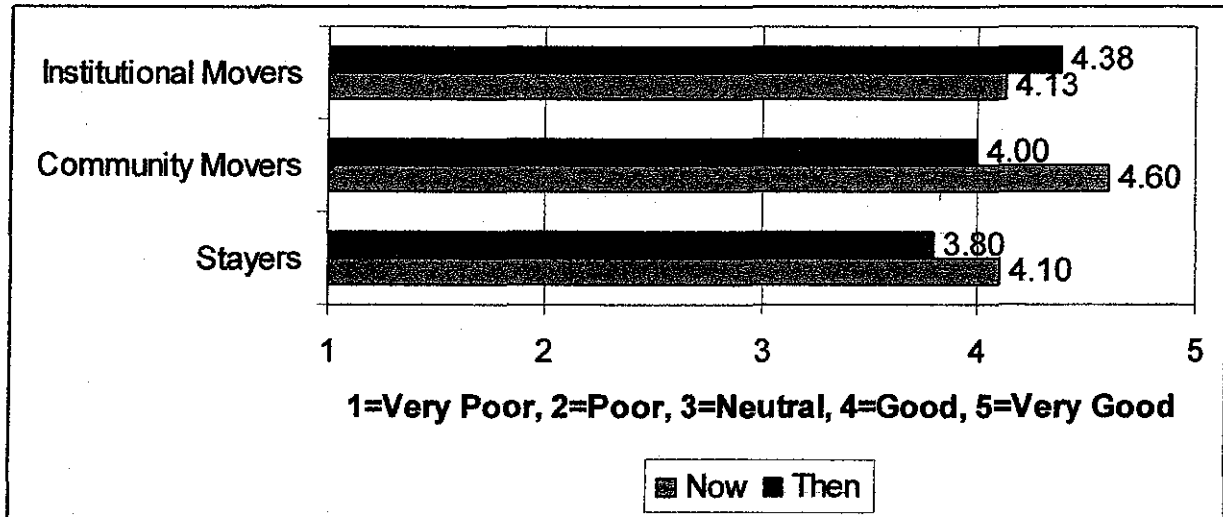


On the average, the relatives of people in all three groups believed the people were between Happy and Very Happy with their homes. The graph suggests that the people who moved to community homes were perceived to be happier than the others, but this difference did not reach statistical significance, and so should not be taken as conclusive.⁵

The survey asked a series of questions about “Qualities of Life, Then and Now” (see Page 4 of Appendix A). The last of the questions was about “Overall Quality of Life,” and it is probably the most interesting. Families were asked to rate their relatives’ qualities of life “Then” (before the announcement of closure) and “Now” (after some of the BHC people moved). The results on that one item are shown in Chart 7.

⁵ We used both parametric and nonparametric tests – Analysis of Variance and the Kruskal-Wallis Test – because of the small numbers – and both reached the same conclusion of non-significant differences among the three groups.

Chart 7: Overall Quality of Life, Then and Now



The answers were given on 5 point scales, with higher scores meaning better quality of life. For the “Institutional Movers” group, the people who moved out of BHC and went to other large facilities, there was a slight drop in the average rating from “Then” (4.38) to “Now” (4.13). But this drop was not statistically significant, and really meant “no change.” For the Community Movers, there was an increase in perceived Overall Quality of Life from 4.00 to 4.60, and by two kinds of statistical test, this change was significant – meaning the increase was larger than could be expected just from chance variations in scores. *But there were only six families in this group* – hence interpretations of the importance of this finding must be made only with the greatest caution.

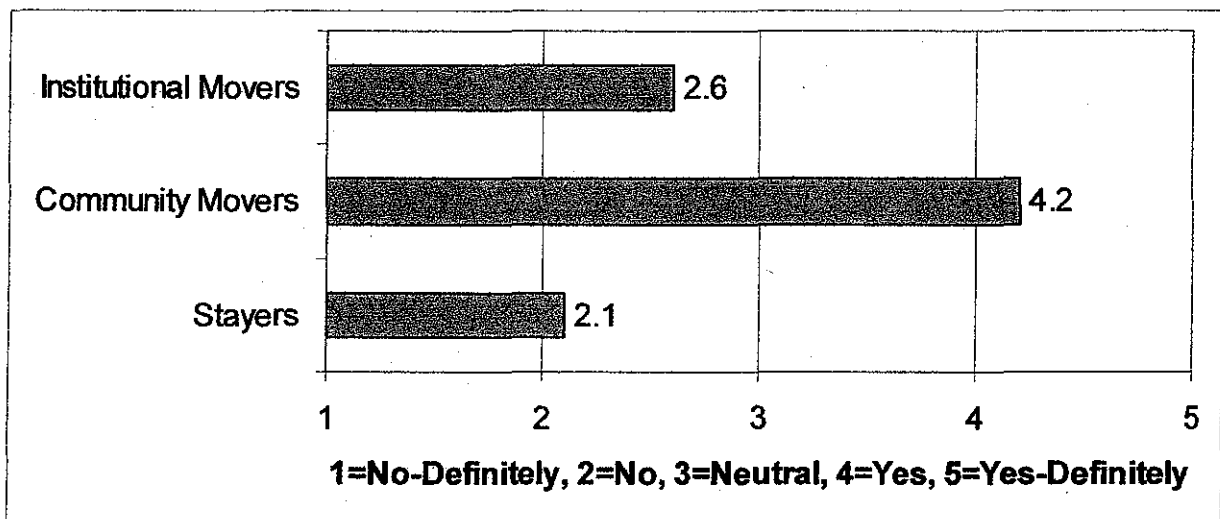
The data also showed that the families of the people who remained at BHC thought that their lives had improved, too – and this was also statistically significant. It seems likely that the reduction of the number of people at BHC caused an increase in perceived quality.

We also checked all the items on the Qualities of Life Then and Now page, and found that none of them changed for the Institutional Movers, while several

items appeared to increase for the Community Movers and the BHC Stayers. For the community folks, the changes were in “Getting out and getting around” and “Food” – for the BHC Stayers, the changes were in “Safety,” “Comfort,” and “Getting Needed Services.”

The families responded to the question “*Would you recommend to other families of people at Bellefontaine that they allow their relatives to move to new homes?*” as shown in the Chart below.

Chart 8: Would You Recommend Movement to Other Families?

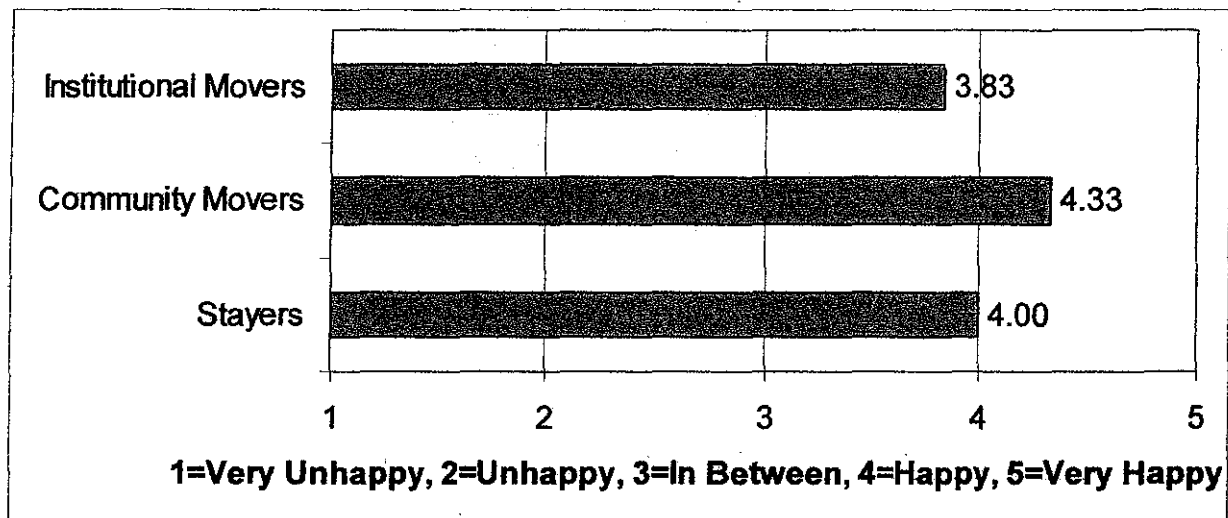


The answers were again given on a scale from 1 to 5, and the Chart shows the average scores given by the families in the three groups. It is no surprise that the families of the Community Movers were the most likely to recommend movement – although the high score also suggests very high success in the community moves – yet again, we must emphasize that this finding comes from only 6 families.

The next question was “*How happy do you think your relative is with his/her day program or job, or whatever he/she does during the day?*” This is a

very important part of the quality of life complex. Just like any citizen, what the BHC people do all day, every day, is central to enjoyment and fulfillment. The chart summarizes the responses.

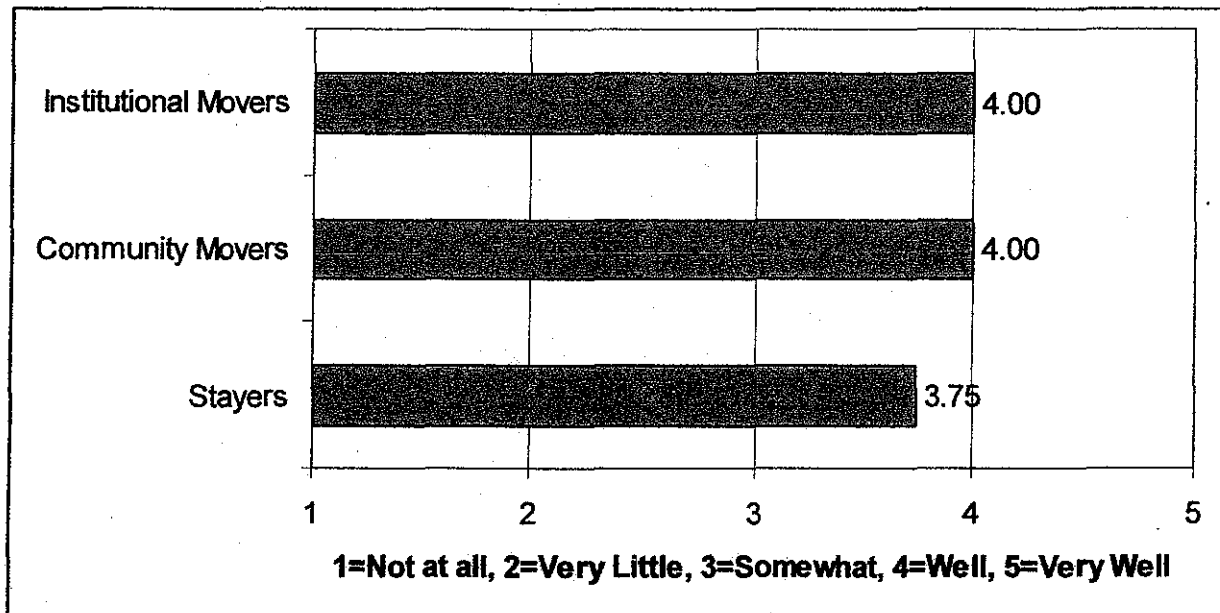
Chart 9: How Happy Is Your Relative with Day Activities?



Within the limitations imposed by the small number of families in the survey, the trend appears to suggest that the Community Movers are happiest with what they do all day. These results did not reach statistical significance, and should be cautiously interpreted as “no difference among the three groups.” But overall, the people were perceived to be “Happy” with their daily activities.

Families of people in our public institutions want and deserve to be kept informed of any changes in the status of, and plans for, their relatives, so we asked: *“Looking back, how well were you kept informed about what was happening with your relative during planning for community placement?”*

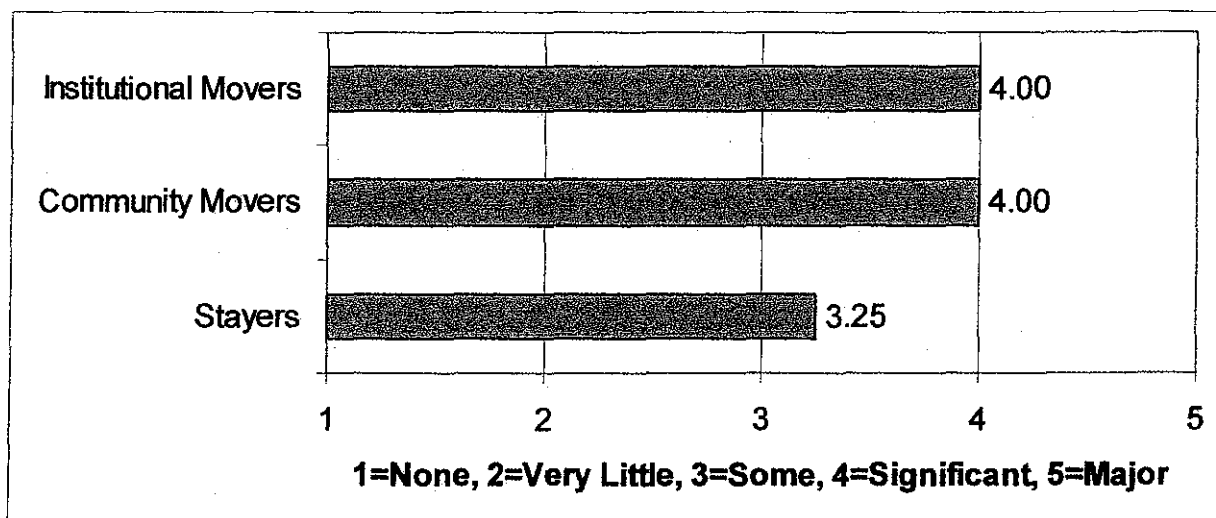
Chart 10: How Well Were You Kept Informed?



The three groups were about equal on this question, although there was a slight (non-significant statistically) suggestion that the families of the Stayers felt less well-informed.

For the families of people living in public institutions, an overwhelmingly important issue is consideration of their opinions and desires. We asked: *"How much attention was given to your opinion about what was best for your relative during the movement from institution to a new home?"*

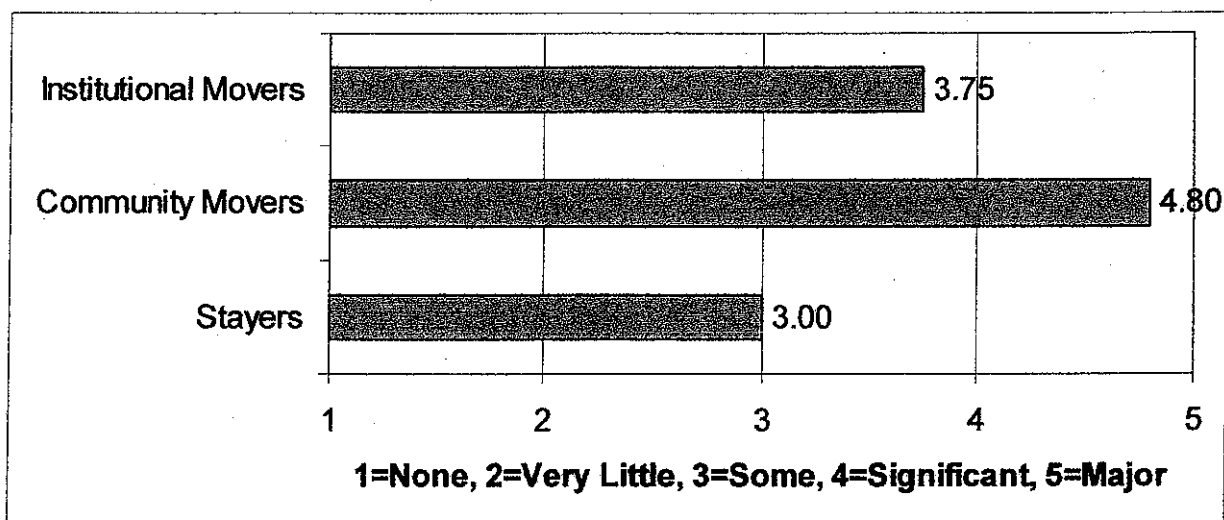
Chart 11: How Much Attention Was Given to Your Opinions?



All three groups felt that their opinions had been given weight, but the families of the Stayers felt less empowered than the others in our survey sample – but because the difference was not statistically significant, we should interpret the findings as all three groups being about equal.

A key issue for the future is tapped by our survey question: *“Right now, how much input do you have in major decisions about your relative’s life, like where to live, with whom, what to do during the day, recreation, worship, and so forth?”* Families need to feel empowered to help set the course of their relatives’ lives, particularly after they are gone. These results were some of the most compelling of the entire survey.

Chart 12: How Much Input Do You Have Right Now?



Despite our very small sample sizes, these results reached very strong statistical significance, meaning that the results were by no means random – they represented something very real. The families of the Community Movers had far and away more feeling of empowerment and input about their relatives' fates than either of the other two groups.

This is of particular interest, despite the very small numbers of families in this survey, because it may be the single most important issue for families of people living in our institutions: *'Will I be able to control, or influence, what the government does with my relative?'* Even though the finding represented in Chart 12 fits with the findings of past studies (see Appendix B), the size of the difference is striking. Families that desire to control what happens to their relatives might consider this in the future – community programs may offer far more individualized choice-making opportunities. As always, we must repeat the caveat that this Missouri finding arises from only 6 “Community Mover” people and their families – yet it matches what has been found in very large samples in past studies.

Results: Direct Quotes From the Relatives and Guardians

The Family Survey asked four open-ended questions at the end of the form:

(24) Please list one or more things that you like about your relative's current situation.

(25) Please list one or more things that you are most concerned about with regard to your relative's current situation.

(26) Was there anything especially good or bad about the way these changes with Bellefontaine were announced and implemented?

(27) If you had one wish for your relative, what would it be?

These comments are valuable for the insights they provide into what the families and guardians have felt and experienced.

The comments are broken out into the three groups – the families and guardians of people who:

1. Stayed at Bellefontaine (“Stayers”)
2. Moved to other large facilities (“Institutional Movers”)
3. Moved to new small community homes (“Community Movers”)

(24) Please list one or more things that you like about your relative's current situation.

Bellefontaine Stayers

Comments from relatives and guardians of people still living at Bellefontaine

- Good the staff is very nice
- For the most part it is a safe environment.
- Taken care of.
- There is a pool table in the home that keeps [him] busy. He gets out more often. Still needs more, but there has been some improvement.
- Good supervision, convenient to programs and social activities at BHC.
- She is always clean and she is always in a good mood.
- Private homes have more abuse.
- He appears to be well cared for and the staff attempts to meet his needs.
- Caregivers concern for her welfare
- Home like atmosphere with many of the same girls since she has been at BHC. This is her home and she is happy! BHC is her safety zone, the staff enjoys her humor!

Institutional Movers

Comments from relatives and guardians of people who moved to other large institutional settings

- [He] is well cared for and as happy and content as is possible.
- It's a mental health facility
- Clean, Open - Church is readily available for him
- Similar to Bellefontaine Campus, Location is good
- She has a nice bedroom with one girl, and she gets out every day.
- Seems content in new surroundings

Community Movers

Comments from relatives and guardians of people who moved to new community homes

- Freedom to play with his toys
- She is comfortable and relaxed. She is totally content and very much at home. The people that take care of her really seem to care. She is very clean.
- She is happy.
- He seems a lot happier, he gets to come home more often.

#24 Interpretive notes: The comments of the families of people who stayed at BHC, and the families of those who moved to other institutions, reflected primarily simple issues of quality of care: being kept busy, location, bedroom, surroundings, safety, and freedom from abuse. We see a contrast with the comments of the six families of people who moved to community settings, which emphasized increased happiness and freedom.

(25) Please list one or more things that you are most concerned about with regard to your relative's current situation.

Bellefontaine Stayers

Comments from relatives and guardians of people still living at Bellefontaine

- I can't explain to him
- Ward needs socialization and development of social skills.
- Do not want him removed from Bellefontaine Habilitation Center
- Gov. Blunt wants to close BHC. He doesn't want to do that, there will be no safety. What needs to be done is a commitment to that facility, the residents and the staff.
- About being moved.
- Safety and caring.
- I do not want him moved from BHC because I believe he feels that this is home for him.
- That she will be moved!
- Being moved from the only home she has ever known. Doesn't do well with change! Would need to be heavily sedated on a regular basis if moved from her familiar surroundings.

Institutional Movers

Comments from relatives and guardians of people who moved to other large institutional settings

- His aggressive behavior at times.
- Being too far away from her family
- He is very bored - He needs to be kept busy and wants to earn money to go places. I worry about his medical and safety needs.
- Dental Care
- She has a health problem and I'm concerned they won't pick up the symptoms soon enough. She was in the hospital three times in as many months in 2006.

Community Movers

Comments from relatives and guardians of people who moved to new community homes

- Physical therapy not provided
- We are very satisfied and really don't have any concerns.
- Turnover of employees with [agency name].
- He would like to earn more money, he just gets an allowance that doesn't go very far, like \$12.

#25 Interpretive Notes: The concerns of the Stayers tended to emphasize fear of movement – families want their relatives to remain at BHC – understandable, after so many years of living there. Families of people who moved from BHC to another large facility reported concerns about care and quality issues – being kept busy, being far away, dental care, and health problems. Families of Community Movers mentioned three disparate concerns: service not delivered, turnover, and employment.

(26) Was there anything especially good or bad about the way these changes with Bellefontaine were announced and implemented?

Bellefontaine Stayers

Comments from relatives and guardians of people still living at Bellefontaine

- Good
- The announcement created a great deal of uncertainty , which still exists
- They were terrible.
- The decision to close BHC by the Governor and Dr. Keith Schafer has caused much strain on all who would be affected by that decision.
- It was handled good.
- Moving my child around at Bellefontaine is not a good thing. Changing workers is a bad idea.
- Yes, adequate explanations were never given.
- So far, not sure if our wishes matter
- No opinion

Institutional Movers

Comments from relatives and guardians of people who moved to other large institutional settings

- Bellefontaine handled the transition very well, helped with placement I was pleased. The govt, on the other hand - was wrong in trying to close Bellefontaine
- Changes at BHC began about 6 years ago with staff -less of them and more work for them. Then the grounds and Buildings got bad and Then Johns care seemed less important. No tax money was the cause in my opinion.
- No one twisted my arm to move my daughter, since they were supposed to close. So I started looking before I had to move her, and Emmaus has a good name + there is a Emmaus house close to me that I would move her to if ever an opening comes up.
- We were told by transitional person there would be activities which did not come about, because of funding.

Community Movers

Comments from relatives and guardians of people who moved to new community homes

- The governor could have been more tactful than the way it was dumped on us about closing Bellefontaine, but we feel it was best for our child to be moved.
- No comment.
- It was okay.

#26 Interpretive Notes: The comments of the families of Stayers were mainly negative. They mentioned uncertainty, poor communication, and confusion. The families of people who moved to another large facility were generally pleased with the process. Families of Community Movers said the process might have been improved, but the outcome was very good.

(27) If you had one wish for your relative, what would it be?

Bellefontaine Stayers

Comments from relatives and guardians of people still living at Bellefontaine

- Stay where he is
- Appropriate placement in the community
- Care at Bellefontaine Habilitation Center.
- His happiness and health.
- That he could live out his life at BHC, as he has done for the last 45 years.
- To stay where she is at.
- Leave her in one home with same workers that she is close to.
- That he would remain at BHC and more money from the State would be allocated for upkeep.
- To remain at BHC
- She could continue to live in a safe and secure environment.
- To remain at Bellefontaine with familiar surroundings and staff.

Institutional Movers

Comments from relatives and guardians of people who moved to other large institutional settings

- Peace of mind and body.
- To Be Happy
- That he could have all that he once had at Bellefontaine 10 years ago. I would then take him back there in a heartbeat
- Happiness/Safety
- For my daughter to be able to live at home.
- That her care and treatment is geared to her needs

Community Movers

Comments from relatives and guardians of people who moved to new community homes

- To be healthy.
- Happy in his surroundings
- That she continues to be happy and healthy and well cared for as she is now.
- Peace and happiness.
- That he could be able to work and make some extra money, that is important to him.

#27 Interpretive Notes: The wishes of the families of Stayers emphasize continued living at the BHC, because of the familiarity and safety. The families that changed from BHC to other large facilities had wishes of happiness, safety, and the assurance of their needs being met adequately. The Community Mover families expressed wishes for happiness, health, and jobs to make money.

Appendix A

Family Survey Instrument

The Bellefontaine family survey form was derived from 30 years of our work surveying the families of people in institutions and communities. The first such surveys were conducted with families of people living at Temple University's Woodhaven Center in 1975. The Pennhurst Longitudinal Study's family surveys were the next generation of such studies, followed by work in Arizona, Arkansas, California, Connecticut, Colorado, Georgia, California, Indiana, Kansas, Massachusetts, New Hampshire, North Carolina, and Oklahoma.

The Bellefontaine family survey was designed with one consistent question in mind: "Are the class members better off than they were before?"

The survey therefore included questions about beliefs, attitudes, memories of past attitudes, satisfaction, perceptions of qualities of life, perceptions of changes in qualities of life, positive perceptions, negative perceptions, aspirations, and valued outcomes.

**SURVEY OF FAMILIES AND GUARDIANS
OF PEOPLE WHO LIVE, or ONCE LIVED
AT BELLEFONTAINE HABILITATION CENTER**

This survey is about:

We sent this survey to you because you said in a mail request that it would be OK to include you and your relative in a Quality Tracking Project, to find out how he or she is doing during all the changes going on with Bellefontaine.

Your name: _____

(1) How are you related to this person? (PLEASE CIRCLE ONE CHOICE)

1 Mother	2 Father	3 Mother and Father (answering together)	4 Sister or Brother	5 Grand- parent(s)	6 Aunt or Uncle	7 Non-Relative (Guardian, Friend)
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8 Other (PLEASE SPECIFY): _____

(2) Are you the legal guardian or conservator for this person? (PLEASE CIRCLE ONE CHOICE)

1 Yes Full legal guardian	2 Yes Limited legal guardian	3 Yes Legal Conservator	4 No
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(3) How old are you? (If two people are answering, please use either one's age or the range that fits both of you the best.

1 Under 20	2 20-29	3 30-39	4 40-49	5 50-59	6 60-69	7 70-79	8 80 or over
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Optional: Exact age _____ years

(4) Where is your relative living right now?

1 Bellefontaine Habilitation Center	2 A community home, like a group home or apartment, with 6 people or less	3 Another large facility (large meaning more than 15 people live there)	4 Some other place
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For any place other than Bellefontaine, what is the name of the facility and where is it?

(5) **About** how many years did your relative (or ward or friend) live at Bellefontaine Habilitation Center? (If still there, how many years has he/she lived there?)

_____ years or ____ Check If You Don't Know

(6) Roughly when did your relative leave Bellefontaine? (Just the year, if you don't know the month.)

<input type="checkbox"/> Check here if your relative is Still At Bellefontaine	_____ Month Left	_____ Year Left	<input type="checkbox"/> Check here if you Don't Know
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(7) **About** how many contacts of each kind in the past year have you had with your relative?

About how often in the past year? (Zero if none)	Type of Contact
	a Telephone calls
	b Mail
	c I (we) visited him/her at his/her home
	d I (we) took him/her for an outing, or to our home
	e Went to a Program Planning Meetings
	f Consent for medical care

(8) When you first heard about the idea of your relative moving to a new home, were you "for" it or "against" it?

1 Strongly Against	2 Against	3 In Between	4 In Favor	5 Strongly In Favor	9 No Opinion, Don't Know, Can't Answer, Not Applicable
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(9) How do you like your relative's home now?

1 Dislike A Lot	2 Dislike	3 In Between	4 Like	5 Like A Lot	9 Don't Know, No Opinion, Can't Answer
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(10) How happy do you think your relative is with his/her current living situation?

1 Very Unhappy	2 Unhappy	3 In Between	4 Happy	5 Very Happy	9 Don't Know
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(11) How many people does your relative live with now?

_____ number of people in the entire facility

_____ number of people in the house, apartment, or living unit

_____ number of people with whom your relative shares a bedroom

(12) QUALITIES OF LIFE, THEN AND NOW

Please circle numbers to describe your opinions about the qualities of your relative's life **THEN**, when living at Bellefontaine, and his/her qualities of life **NOW**, in a new home. For any items that you don't know, just don't circle anything. Please use the scale below to rate each area.

If your relative is still living at Bellefontaine, please use "a couple of years ago" for "**THEN**."

1 Very Poor	2 Poor	3 In Between	4 Good	5 Very Good
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THEN: AT BELLEFONTAINE	QUALITY AREA	NOW: IN NEW HOME (or BHC if still living there)
1 2 3 4 5	a Relationship with family	1 2 3 4 5
1 2 3 4 5	b Relationship with friends	1 2 3 4 5
1 2 3 4 5	c Getting out and getting around	1 2 3 4 5
1 2 3 4 5	d What he or she does all day	1 2 3 4 5
1 2 3 4 5	e Safety	1 2 3 4 5
1 2 3 4 5	f Treatment by staff/attendants	1 2 3 4 5
1 2 3 4 5	g Food	1 2 3 4 5
1 2 3 4 5	h Happiness	1 2 3 4 5
1 2 3 4 5	i Health	1 2 3 4 5
1 2 3 4 5	j Dental care	1 2 3 4 5
1 2 3 4 5	k Making Choices	1 2 3 4 5
1 2 3 4 5	l Privacy	1 2 3 4 5
1 2 3 4 5	m Comfort	1 2 3 4 5
1 2 3 4 5	n Work or day program	1 2 3 4 5
1 2 3 4 5	o Getting needed services	1 2 3 4 5
1 2 3 4 5	p Overall quality of life	1 2 3 4 5

(13) Would you recommend to other families of people at Bellefontaine that they allow their relatives to move to new homes?

1 No, Definitely Not	2 No, Probably Not	3 In Between	4 Yes, Probably	5 Yes, Definitely	9 Don't Know, Can't Answer, Not Applicable
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(14) How happy do you think your relative is with his/her day program or job, or whatever he/she does during the day?

1 Very Unhappy	2 Unhappy	3 In Between	4 Happy	5 Very Happy	9 Don't Know, Can't Answer, Not Applicable
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(15) How happy are you with your relative's day program or job, or whatever he/she does during the day?

1 Very Unhappy	2 Unhappy	3 In Between	4 Happy	5 Very Happy	9 Don't Know, Can't Answer, Not Applicable
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(16) Do you know your relative's case manager or service coordinator?

1 Yes	2 No	9 Not Sure
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(17) How satisfied are you with your relative's case manager or service coordinator?

1 Very Unhappy	2 Unhappy	3 In Between	4 Happy	5 Very Happy	9 Don't Know, Can't Answer, Not Applicable
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(18) Looking back, how well were you kept informed about what was happening with your relative during planning for community placement?

1 Not At All: Always found out about things after they happened, if at all	2 Very Little: Usually found out afterward	3 Somewhat: Sometimes knew, sometimes didn't	4 Well: Usually knew in advance what was happening	5 Very Well: Always informed in advance about what was being planned	9 Don't Know, Not Applicable
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(19) How much attention was given to your opinion about what was best for your relative during the movement from institution to a new home?

1 None	2 Very Little	3 Some	4 Significant	5 Major	9 Don't Know, Not Applicable
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(20) Right now, how much input do you have in major decisions about your relative's life, like where to live, with whom, what to do during the day, recreation, worship, and so forth,?

1 None	2 Very Little	3 Some	4 Significant	5 Major	9 Don't Know, Not Applicable
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(21) Right now, how satisfied are you with the amount of input you have regarding the major decisions in your relative's life like where to live, with whom, what to do during the day, and so forth?

1 Very Unhappy	2 Unhappy	3 In Between	4 Happy	5 Very Happy	9 Don't Know, Can't Answer, Not Applicable
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(22) FIVE MOST IMPORTANT THINGS

In the section below we would like to know what the five most important things are to you and to your relative concerning his or her well-being.

Please read through the list below and determine which of these is the #1 most important thing to you about your relative's well-being? Please write a "1" next to that item. Then, please write a "2" next to the SECOND most important thing to you. Please continue writing numbers up to 5, for the fifth most important thing to you.

Important to You	
_____	Assistive devices
_____	Being kept busy
_____	Being with other people with disabilities
_____	Choicemaking
_____	Comfort
_____	Communication
_____	Community acceptance
_____	Supports for problematic behavior
_____	Development, learning
_____	Dignity, respect
_____	Earn money
_____	Exercise, fitness
_____	Family-like atmosphere
_____	Freedom from abuse
_____	Friends
_____	Girlfriends/Boyfriends
_____	Health
_____	Home-like place
_____	Integration, inclusion
_____	Large facility to live in
_____	Love
_____	Medical attention
_____	Permanence of home
_____	Productive day activities
_____	Religion, worship
_____	Safety
_____	Self esteem
_____	Self-care skill development
_____	Self-determination
_____	Stability
_____	Travel, vacations
_____	Working for pay

(22) How satisfied are you with the degree to which these five "most important things" have been attained and/or accomplished?

1	2	3	4	5	9
Very Unhappy	Unhappy	In Between	Happy	Very Happy	Don't Know, Can't Answer, Not Applicable

(23) Do you and your relative differ on what's most important in the list above? If so, please describe one or two areas.

1 No, we don't differ about what's important for a quality life	2 Yes, we differ on one or more things about what's important	9 Don't Know, Can't Answer, Not Applicable
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If you answered 2, Yes, above, could you please give a brief example?

POSITIVES AND NEGATIVES

(24) Please list one or more things that you like about your relative's current situation.

(25) Please list one or more things that you are most concerned about with regard to your relative's current situation.

(26) Was there anything especially good or bad about the way these changes with Bellefontaine were announced and implemented?

(27) If you had one wish for your relative, what would it be?

(28) Your answers can be kept completely confidential, or if you wish, we can tell officials what you said without saying who you are, or we can tell officials what you said and who you are so they can contact you and/or address any concerns you or your relative may have.

1 Keep confidential	2 Tell them what I said, but don't use my name or my relative's name	3 Tell them what I said with our names
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THANK YOU!

Appendix B

Prior Research on Families and Deinstitutionalization

Surveys of the families of people with developmental disabilities are becoming a more frequently used and valued tool for assessing the quality of services (Arc-US, 1989; Conroy & Bradley, 1985; Covert, Hess, & Conroy, 1985; Larson & Lakin, 1991). The present efforts to monitor family perceptions of the well being of Bellefontaine class members who moved to community homes should be seen as part of that trend.

Past research at the national level has clearly established the fact that families of people in public institutions are highly satisfied with these facilities (Spreat, Telles, Conroy, Feinstein, & Colombatto, 1987). Most families are opposed to changes, and most are particularly opposed to community placement.

In one of the earliest studies, Klaber (1969) surveyed parents of people in institutions in Connecticut. He found that more than three fourths of them believed that the institutions were extremely high quality. He concluded that "The parents ... were convinced of the excellence of the facilities in which their children were placed ... The praise lavished on the institutions was so extravagant as to suggest severe distortions of reality in this area."

Brockmeier (1975) reported similarly high levels of satisfaction, coupled with skepticism about community-based care, among families of people in Nebraska institutions. Payne (1976) discovered the same situation in Texas. Payne was also the first to identify a "deinstitutional backlash." He characterized the backlash group as a loosely knit countermovement of various local and statewide associations of parents organized in support of institutions as opposed to community residential facilities.

Willer, Intagliata, and Atkinson (1979) reported overwhelming satisfaction among families of institutionalized people in New York state.

Meyer (1980) found that over 70% of families of people in an institution in Western Pennsylvania were satisfied with the services provided by the facility, and they opposed the idea of community placement.

Keating, Conroy, and Walker (1980) found as part of the Pennhurst Longitudinal Study that 83% of families were "satisfied" or "very satisfied" with Pennhurst, even at the height of court and media criticism of Pennhurst. Moreover, 72% strongly opposed the idea of community placement.

Frohboese and Sales (1980) reported that families in Nebraska believed the state institution to be the least restrictive alternative feasible for their relatives. They perceived greater freedom of movement, independence, and safety within the institution. The greatest concern expressed by these families about deinstitutionalization was their perception of the lack of permanence of the community settings. These authors also described the possibility of legal and ethical conflict between the rights of parents and the rights of people with disabilities.

Atthowe and Vitello (1982) detected similar feelings among families in New Jersey. In their survey, 54% expected no more than custodial care, and 91% said the institutional care was adequate or better. More than 80% wanted their relatives to remain in New Jersey's institutions.

Conroy (1984) surveyed the families of 1611 people living in institutions in Pennsylvania who had been "nominated" for movement to the community. No fewer than 91% of families were "satisfied" or "very satisfied" with institutional services, and 81% were "opposed" or "very opposed" to the idea of community placement.

Conroy (1987) found in Georgia that 72% of the families of people at Georgia Retardation Center were "Very Satisfied" with services provided to their relatives. They overwhelmingly opposed the idea of movement to community services.

Spreat, Telles, Conroy, Feinstein, and Colombatto (1987) conducted a national survey of the families of people in public institutions. The survey revealed very high satisfaction with the institutional settings, plus resistance to community services. Overall, 61% of families rejected the idea of "a group home of about six beds, located in a regular residential area, staffed 24 hours so that clients are never left alone, and from which every client goes to a day program (school, workshop, job)." The survey also showed that resistance to community services was higher among families of people with the most severe impairments.

The nation's first report of changes in attitudes after movement from institution to community was published by Latib, Conroy, and Hess (1984). They surveyed Pennsylvania's Pennhurst families before and after community placement. They found that the families' initial opposition changed dramatically to overwhelming satisfaction with, and support for, community living.

Covert, Hess, and Conroy (1985) surveyed families after their relatives left the Laconia State School in New Hampshire. According to family recollections,

only 38% had been "satisfied" or "very satisfied" with the situation at Laconia, whereas 84% said they were satisfied or very satisfied with their relatives' current community residences.

Conroy and Wang (1987) reported on Connecticut research tracking more than 1300 people. For people who moved from institutional to community settings, family satisfaction and the perceived happiness of the relative increased sharply.

Conroy, Lemanowicz, and Bernotsky (1991) extended the prior work of Conroy & Wang (1987). They surveyed the families of 101 deinstitutionalized people in Connecticut before and after community placement. The survey contained nine items related to quality of life and satisfaction (e.g., satisfaction with the home, with day program, food, privacy). All nine items increased significantly, with improved privacy and satisfaction with the residential setting showing the largest positive changes.

Grimes and Vitello (1990) examined the attitudes of 32 families of deinstitutionalized people who had been living in the community for 3 to 7 years. Preplacement data on these families (Atthowe & Vitello, 1982) had shown a high level of satisfaction with institutional services and strong opposition to community placement. The postplacement survey revealed a significant change toward more positive family attitudes toward deinstitutionalization.

Temple University's 1990 survey of all the families of people who once lived at Pennhurst (Lemanowicz, Levine, Feinstein, & Conroy, 1991) revealed that only 6 of the 420 responding families were "Strongly Dissatisfied" with community living. Many of the families wrote comments describing how surprised they were with the quality of life enjoyed by their relatives in community homes. Many wrote that they were amazed that they had ever opposed the move from institution to community.

Larson and Lakin (1991) wrote a review article based on all of the family deinstitutionalization attitude studies of the preceding two decades. They performed a meta-analysis upon the results of 27 such studies which examined the attitudes and perspectives of parents of currently or formerly institutionalized people. Larson and Lakin summarized: "The clearest message in these studies is that the overwhelming majority of parents become satisfied with community settings once their son or daughter has moved from the institution, despite general predispositions to the contrary."

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